How Treatment Partners Help: Social Analysis of an African Adherence Support Intervention

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How Treatment Partners Help: Social Analysis of an African Adherence Support Intervention

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Abstract Treatment partnering is an adherence intervention developed in sub-Saharan Africa. This paper describes the additional social functions that treatment partners serve and shows how these functions contribute to health and survival for patients with HIV/AIDS. Ninety-eight minimally structured interviews were conducted with twenty pairs of adult HIV/AIDS patients ($N = 20$) and treatment partners ($N = 20$) treated at a public HIV-care setting in Tanzania. Four social functions were identified using inductive, category construction and interpretive methods of analysis: (1) encouraging disclosure; (2) combating stigma; (3) restoring hope; and (4) reducing social difference. These functions work to restore social connections and reverse the isolating effects of HIV/AIDS, strengthening access to essential community safety nets. Besides encouraging ARV adherence, treatment partners contribute to the social health of patients. Social health as well as HIV treatment success is essential to survival for persons living with HIV/AIDS in sub-Saharan Africa.

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Resumen Tratamiento asociarse es una adhesión intervención desarrollado en el África subsahariana. Este documento describe las funciones sociales que el tratamiento socios servir y muestra cómo estas funciones contribuyen a la salud y la supervivencia para pacientes con VIH/SIDA. El Noventa y ocho mínimamente estructurada se realizaron entrevistas con veinte pares de adultos con VIH/SIDA pacientes ($N = 20$) y el tratamiento asociados ($N = 20$) tratada en un público VIH-cuidado en Tanzania. Cuatro funciones sociales fueron identificados mediante inductivo, categoría construcción interpretativa y métodos de análisis: (1) alentando revelación; (2) lucha contra el estigma; (3) restaurar la esperanza; y (4) reducir diferencia social. Estas funciones trabajar para restablecer las conexiones sociales y revertir los efectos aislar del VIH/SIDA, fortalecer el acceso a redes comunitarias de seguridad. Además alentar ARV adhesión, el tratamiento socios que contribuyen a la salud social de los pacientes. La salud Social así como tratamiento para el VIH éxito es esencial para la supervivencia de personas que viven con el VIH/SIDA in sub-Saharan Africa.

Introduction

In resource-constrained settings, people rely on family members, friends and neighbors to help make ends meet [1, 2]. This includes sharing resources necessary for daily living. Reliance on others is particularly important for people living with HIV/AIDS, who often need help to adhere to medications and keep health care appointments.

Community support has been repeatedly linked with antiretroviral (ARV) adherence and positive treatment outcomes in resource-scarce environments [3–7]. An ethnographic study conducted in Nigeria, Tanzania, and Uganda explained ARV adherence success in sub-Saharan Africa as a function of patients' desires to fulfill social responsibilities and preserve social capital in essential relationships [8]. Individuals on ARV therapy prioritized adherence by borrowing transport funds, allocating scarce resources in favor of treatment, and "doing without." Help from treatment partners and other family members and friends made this possible, but helpers expected adherence in return. Patients adhered to fulfill expectations, and position themselves to continue to benefit from others' support.

Adherence to first-line drug regimens is particularly important where second-line regimens are not readily available. In Africa, HIV/AIDS treatment program planners have used treatment partners for adherence support. Known by different names in different places (treatment assistants, or treatment supporters) and varying slightly in specific responsibilities, treatment partners (TPs) help individuals prescribed ARV therapy to adhere to the medications. TPs may be family members or friends nominated for the role in response to a clinic recommendation or requirement. As TPs, these individuals assume a measure of responsibility for the adherence success of the patient they support.

Treatment partnering overlaps significantly with other forms of adherence and treatment support, but it also differs in important ways. Unlike directly observed therapy (DOT) and modified directly observed therapy (mDOT) for HIV [9–12], actual observation of pill-taking is not part of the definition of treatment partnering, although it may occur as part of the helping process. TPs also differ from community health workers in that they are not employees of, or based at, a clinic or service organization, and are not paid for their efforts [13–16]. Treatment partners are not formally trained, nor are they asked by clinicians to perform functions (e.g., counseling [17] or home-based care [18, 19]) other than helping to make sure patients follow prescribed dosing regimens.

Efforts to measure the impact of treatment partners on patient clinical outcomes have yielded mixed results. A study conducted in Jos, Nigeria, showed a beneficial effect on drug adherence (measured as clinic-based pill counts) and viral load for participants with patient-selected treatment partners; however, there was no durable effect on viral suppression [20]. A sub-study designed to examine the impact of treatment partners on drug resistance showed no association [21]. A randomized controlled trial of trained patient nominated treatment supporters providing partial directly observed antiretroviral therapy in Cape Town, South Africa, showed no effect on virologic outcomes but greater CD4 cell count increases at 6-month follow-up visits [22]. A randomized controlled trial investigated the impact of treatment support on adherence and clinic attendance in Uganda. The supported patients did not differ from controls in mean adherence (98.3–99% vs. 94.2–98.3%) or in appearing on time for clinic appointments, but they were four times more likely to achieve optimal adherence ($\geq$95%) ($P = 0.027$) [23]. A qualitative study in South Africa identified moral authority as a key ingredient of treatment support, making it possible for supporters to influence health-related decisions [24].

A growing body of U.S. and international research investigating various forms of social support for HIV/AIDS is relevant to understanding treatment partners. Interventions aimed at providing social support through peers (other individuals living with HIV/AIDS) have been shown to impact risk behaviors, and knowledge and attitudes toward HIV [25–27]. A number of approaches to providing couples-based support for adherence and HIV prevention have also been examined [28–35].

Overall, previous research on both treatment partners and other interpersonal interventions has targeted behavioral and biologic outcomes. In contrast, this analysis highlights social consequences of treatment partnering and its significance for the health and well being of individuals living with HIV/AIDS in sub-Saharan Africa.

Methods

A Grounded Theory Approach

This qualitative study used a grounded theory approach. Grounded theory, first described by Glaser and Straus in 1967, refers to systematic generation of theory from qualitative data. Analysis proceeds inductively, beginning with coding, then using coded data to form concepts and categories. Theory is generated interpretively by arranging the categories to propose a general explanatory account.

Study Design and Setting

This patient-centered, qualitative interview study took place at Amana District Hospital, a public HIV-treatment setting in Dar es Salaam, Tanzania. Data were collected from 2006 to 2008. Of 9,500 patients in the HIV clinic, 5,300 were prescribed ARVs at the time of the study. ARVs were provided through the President's Emergency Plan for AIDS Relief (PEPFAR).

Sampling and Recruitment

Twenty adults receiving care and treatment for HIV/AIDS at Amana Hospital and their TPs ($N = 40$ individuals)

made up the sample for this analysis. Patient participants were randomly selected from a larger population of adults meeting the following inclusion criteria: (1) age 18 years or older; (2) prescribed antiretroviral therapy for no fewer than six and no more than 12 months at the time of sampling; and (3) residence within 20 km of Amana District Hospital. To identify potential treatment partner participants, patients were asked to name "someone who assisted them in their efforts to take antiretroviral medications." Treatment partners were part of the clinic's program of support for ARV adherence.

Patient participants were recruited at the clinic during routine follow-up visits. Research assistants approached eligible individuals to describe the study and to extend an invitation to participate. Potential TP participants were initially contacted by patient participants, who presented the study using an IRB-approved script and requested permission for subsequent contact by research staff.

The research was approved by the institutional review boards at Harvard Medical School (Boston, Massachusetts, United States) and Muhimbili University of Health and Allied Sciences (Dar es Salaam, Tanzania). Written informed consent was obtained from all participants.

Data Collection

Data were collected through in-person qualitative interviews as part of a three-country study of social influences on adherence to ARVs. Local researchers trained in qualitative data collection techniques conducted interviews.

Interviews were minimally structured, meaning that core topics, but not specific questions, were pre-designated. This approach ensured the same broad areas were covered in each interview, while allowing unanticipated material to emerge. Core topics for patient interviews included: [1] specific experiences of taking ARVs (e.g., stories of the most recent dose taken and the most recent dose missed); [2] clinic visits; and [3] help received from TPs. Core topics for treatment partner interviews included: [1] types of help provided; [2] feelings about being a treatment partner; and [3] perceptions of the impact of the help provided.

The goal of the interviews was to elicit data on experiences of adherence from patient and treatment partner perspectives. Interviews were conducted in homes or at other locations of the interviewees' choosing outside of the clinic. Conducting the interviews in locations where the conversations could not be overheard protected privacy. Interviewees had the option of conducting the interview in the local language (Kiswahili) or in English. Interviews were audio-recorded with permission and averaged about an hour in length. Patients received compensation in the form of a small stipend and, whenever applicable, reimbursement for transportation.

Multiple interviews were conducted with each patient and treatment partner to allow for elaboration of unanticipated topics of emerging significance. Patients were interviewed three times each (Total Patient Interviews = 60). Thirty-eight interviews were conducted with the 20 TPs. (Total interviews = 98).

Data Preparation

Shortly after the completion of each interview, interviewers produced a detailed write-up in English, using the audio recording and written notes to ensure accuracy and completeness. The interviews were written up as "stream-lined" transcripts. "Stream-lined" transcripts are verbatim verbal accounts that include interviewer questions and interviewee responses, while excluding non-essential content (e.g., hesitations, repetition of phrases). This approach to transcription captures detail and preserves the exact words of interviewees. The transcripts were produced in English (without first transcribing into the local language), and contained a section in which the interviewer added relevant contextual details and impressions not captured in the transcript.

Data Analysis

Analysis was aimed at identifying and representing the functions of TPs using an inductive approach to the construction of descriptive categories [36, 37]. First, content that related to ways TPs helped patients was retrieved from the data. Relevant sections of text were identified, copied, and grouped according to the type of assistance provided. These sections of text were then reread to characterize various forms of help. The data were reorganized in terms of these characterizations to produce an initial category set. Each category forming the set was named, defined, and illustrated through interview excerpts. The set was refined, revised, specified, and elaborated through successive returns to the data in which additional sections of relevant text were extracted. Ultimately, categories were grouped into larger thematic domains termed isolation and integration, to form a narrative explanation of the social functions TPs fulfill

Results

Study Participants

Patients: Two-thirds (68%) of patient participants were female; they averaged 40 years of age. Slightly more than half (53%) were Christian; slightly fewer than half were Muslim (47%). Average number of years of education was

8.5. All patients reported 100% adherence, assessed using the Adult AIDS Clinical Trials Group (AACTG) 3-day self report measure [38]. Mean reported monthly income was 121,290 Tanzanian Shillings (approximately $82 USD), shared by an average of 5.5 people. Mean amount of money available for or spent on food each day was 3,383 Tanzanian Shillings ($2.29 USD); almost half (43%) of patients reported that the family income had been spent entirely on food in the previous month.

Treatment partners: Slightly more than half (55%) of TP participants were female; average age of the group was 41. Fifty-three percent of TPs were Muslim; 47% were Christian. Average number of years of education was 7.4. Participating treatment partners' were related to patients as: [1] spouses (30%), [2] siblings (25%), [3] parents (20%), [4] adult children (5%), and [5] extended family members (5%). Fifteen percent reported another type of relationship. The majority of treatment partners (65%) shared a residence with the patient. The remainder lived a short walk away.

Qualitative Results

Qualitative results are organized into three sections corresponding to the major categories constructed through the inductive analysis. Together, the sections present the logic and supporting data for our central argument: in addition to supporting adherence, TPs work to restore the social health of patients living with HIV/AIDS.

Community As Resource

The interviews depict the daily lives of patient participants as revolving around efforts to cope with economic scarcity. Most of each day was spent working to obtain essential goods such as food and water. Other important resources, such as clothing, medications, health services, transportation and housing, were a lower priority. Routine household tasks, e.g. food preparation and cleaning, were labor intensive, draining time and energy. To sustain themselves in poverty, people relied on others for help.

Who were these helpers? For study participants, helpers included family, neighbors, friends, people with whom they exchanged goods and services, work colleagues and acquaintances from church/mosque or health clinics. These people were their community, the core group they counted on to make ends meet.

Communities provide help in a number of ways, one of the most significant of which is lending money. Patient participants routinely borrowed money from friends and family to meet urgent needs, such as food, medications and transportation to the health clinic. They also borrowed from lending groups, informal organizations in which individuals pooled money and then borrow from the pool when needed. Providing needed funds is one of many ways communities function as resources in settings of economic scarcity. To continue to draw upon community as resource, individuals must be in good standing in the social group.

Isolating Effects of HIV/AIDS

Isolation and Disclosure (and Non-Disclosure)

HIV/AIDS erodes social standing and isolates individuals from the communities they depend on. The risk of disclosure lies in loss of social standing and resulting isolation. One patient participant put it this way:

> "I don't see the reason to tell people. If they have run out on me with regular sickness, not knowing my HIV serostatus, if I tell them [I am HIV-positive] they may run forever."

Isolation from the community means being denied access to needed community resources. As financial borrowers, for example, HIV + persons are seen as poor risks. Potential lenders fear they may not remain healthy long enough to earn the money to repay a loan. In the words of one interviewee:

> "They see it as useless to assist someone who has a shorter time to live. It's like wasting money. Why assist someone who is going to die?"

HIV + persons resist disclosure to avoid isolation and preserve access to community resources; however, non-disclosure can also be isolating. Not disclosing means not being able to ask for help with problems arising from HIV/AIDS. It means hiding medications and clinic visits. Some study participants abandoned their jobs in order to conceal their HIV status. One interviewee explained her decision to stop working this way:

> "I thought that people would know my HIV status when I have illnesses regularly and am out of the office several times."

Non-disclosure may reduce the threat of being stigmatized, but at the cost of weakening essential connections to others.

Demoralization as Isolation

HIV/AIDS is demoralizing. Patient participants in this study spoke of the sadness, discouragement, and anxiety of being HIV + . They described fear of death, and loss of a sense of purpose in life. In the words of one:

> "I thought this was the end of my life. Everything I had for my future plans was useless to me now. I didn't feel like continuing to work, because I thought at any time I am going to die. There is no meaning to work while I suspect to die at any time."

For some, the demoralization of HIV/AIDS led to thoughts of suicide. One individual described suicide as a reasonable alternative to enduring the stigma of HIV/AIDS.

> "It is better to die with malaria, and for people to say I died from malaria. Now with HIV, I desire for committing suicide."

Demoralization fuels isolation by creating a desire for separation and making daily functioning more difficult.

Restoring Social Connection: How Treatment Partners Help

Treatment partner participants in this study included family, neighbors, friends, people with whom patients exchanged goods and services, workmates and acquaintances from churches, mosques, and health clinics. Their designated clinical function was to help with adherence to ARVs. Patient participants cited many forms of adherence help. TPs offered in-person, phone, and text message reminders. They made sure patients had food, to improve medication tolerance. One treatment partner described her considerable efforts to deliver food to a patient in secret so the patient would not be obliged to share it with family members. TPs also helped patients to obtain essential non-food items, such as clothes and cleaning supplies. They reminded patients to attend clinic appointments, often providing or funding transportation themselves.

In addition to promoting ARV adherence, TPs intervened to reverse the isolating effects of HIV/AIDS and strengthen social connectedness. Four ways in which TPs acted to enhance social connection for patients were evident in the study data: [1] encouraging disclosure, [2] combating stigma, [3] restoring hope, and [4] reducing "social difference." These four connecting functions are presented in turn below.

Encouraging Disclosure

Non-disclosure of HIV status is isolating, as it precludes seeking and/or receiving needed support from sympathetic others. Recognizing this, TPs encouraged disclosure by pointing to the support that might ensue. They reminded patients, for example, of the resources, prayers and encouragement that might be forthcoming from religious affiliates. Disclosure re-connects HIV-infected persons to their family and friends by opening the door to communication about HIV/AIDS.

Combating HIV-Related Stigma

TPs actively worked to combat the effects of HIV-related stigma. They intentionally interacted with people known to be HIV positive in public, for example, sharing meals to discredit the myth that common utensils can transmit the virus. Another reported tactic was to publicly criticize individuals who stigmatize persons with HIV/AIDS. One patient participant explained how her treatment partner "warns people who stigmatize the HIV people" by telling them:

> "You know HIV now is common. The sick ones are healthier than the healthier people. Nowadays if you stigmatize the HIV patient you will be taken into court. It's not good to stigmatize the HIV people."

Efforts to minimize stigma strengthen relationships by building solidarity with patients.

Restoring Hope

Patients characterized demoralization as "losing hope." Treatment partners worked to restore hope, or "give hope," as they put it, through a number of deliberate strategies. They countered feelings of loneliness by spending time with patients. They reminded them that they were not alone. They counseled faith in God. TPs also helped create a sense of possibility for patients by citing the potential for change: they could expect to live in good health if they took their medications as prescribed and otherwise followed directions from health care professionals. The following excerpts illustrate:

> "He [patient] lost hope when he was very sick. He thought he couldn't be healed. I gave him hope by insisting that he follow the instructions given at the clinic."
>
> "I gave her an example of some people who have been on ARV medication and they have shown positive health progression to give her courage."

Reducing Social Difference

HIV/AIDS increases poverty by interfering with income generation. Interference stems both from poor health and from time diverted from income generating activities. One way impoverishment becomes visible is through deterioration in number and quality of possessions. When clothing wears out and cannot be replaced, for example, it signals social difference. Individuals wearing torn and dirty

clothing "stand out," suffering humiliation as a result. Recognizing this, TPs take steps to erase evidence of social difference. For example, they may buy a patient new clothes. The following citations illustrate:

> "I [buy clothes for the patient] so she can see she's a normal person, to make her feel normal like other people. Once we are not assisting her in that way, she will feel stigmatized."
> "I assist her with clothes to make her feel like other people and not feel she is neglected because of her HIV status."

Thus we see how in this low-resource setting, the community serves as an essential resource. Being able to rely on the community to help obtain goods and complete daily tasks is critical to survival. HIV/AIDS isolates individuals from the community. Treatment partners restore social connections and reintegrate persons living with HIV/AIDS into the community.

Discussion

In addition to promoting medication adherence, TPs play an important social role in the lives of the patients they help. They encourage disclosure, combat stigma, restore hope, and reduce social difference. All of these are ways of "normalizing" HIV/AIDS – of reversing social isolation and reinstating connections to others.

As a strategy for adherence support, TPs are a natural fit for social settings where reliance on others is the norm. The treatment partner model formalizes existing helping relationships and uses them to promote treatment success. The socially integrating aspects of treatment partnering have not previously been made explicit.

Social embeddedness promotes health [39–41] for persons living with HIV/AIDS [42]. In settings of poverty, strong interpersonal relationships are needed for survival. Where resources are scarce, reliance on "community safety nets" [43] helps to bridge inevitable gaps. In strengthening social connectedness, TPs ensure patients' continued access to safety nets.

Though suggestive, the small amount of experimental evidence evaluating the impact of TPs on clinical outcomes does not clearly demonstrate the superiority of the intervention compared to standard controls. Multiple studies have revealed short-term positive effects, which diminished over time [20–22]. Where helping is the norm, failure to detect large effects may be a function of levels of informal support in the control group.

This analysis supports previous claims about the importance of qualitative methods in contributing to research on treatment interventions for HIV/AIDS [44]. The qualitative design included multiple perspectives (including those of TPs) in the study sample, and adopted an inductive approach to data collection and analysis. As a result, we were able to uncover new functions of an adherence intervention and explain their relevance to health and survival for persons living with HIV/AIDS in sub-Saharan Africa.

We acknowledge the limitations of this work. As a qualitative analysis, it does not quantitatively assess the impact of treatment partnering upon clinical or other outcomes. The relative contributions of specific connecting functions cannot be quantitatively estimated. The sample is small and reflects a single geographic location and a single treatment program. Qualitative research does not aim for generalizability; hence broader inferences cannot be drawn from the results.

Conclusion

HIV/AIDS has profound social and health consequences, isolating HIV + persons from social reference groups. TPs are charged with promoting ARV adherence, but they provide important social help as well. This analysis details the ways in which TPs rebuild social ties and restore the social standing of HIV + persons in their communities. Good social standing means help from others will be available when needed. Where resources are otherwise scarce, help from others is critical for coping with adversity. In establishing treatment partners as an adherence intervention, African treatment program planners may have enhanced the social and physical health of persons with HIV/AIDS.

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